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The journal is the official publication of Australian and New Zealand professional nursing groups caring for babies, children and their families. The three organisations represent a diversity in nursing, ranging from intensive care nursing to the community-based nursing services, found in cities and remote areas throughout Australia and New Zealand.

The journal will endeavour to reflect this diversity by its content. Neonatal, paediatric and child health nursing have many different aspects that may be relevant to more than one sector of the membership. In addition to clinically oriented material, including research, the journal also provides a forum for articles on professional aspects of nursing that apply to all nurses and in particular to nurses working with babies, children and families.

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Quality palliative care for all children*—realising the vision

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Palliative care for children has emerged as a small but discrete area of practice internationally, as the number of children requiring such care increases. Although a relatively small number, this group of children and families requires intense and sustained support alongside specialist services for the duration of the child’s life as well as for several years beyond. Whilst childhood cancer now experiences higher cure rates it is actually children with non-malignant conditions that constitute the greatest proportion of those (60%) requiring palliative care. Such a shift can be attributed partly to technological advances, resulting in growing numbers of medically vulnerable children experiencing improved survival. Unfortunately many of these children will not survive to adulthood, necessitating a palliative approach to care.

In this issue, Bradford and colleagues highlight a number of gaps and barriers raised by parents and professionals as leading to challenges when providing palliative care for children in Queensland. Evolved from established palliative care services within the children’s oncology centre, their work endorses the recognised need to develop care and services for children with non-malignant conditions, who experience different trajectories and specific needs. Despite recent strides within service development across countries, the pace of developments and gaps in service still vary depending on location. (An example being that palliative care services for children in rural Queensland can be limited, something that resonates with care in parts of, for instance, rural Ireland.) However, I would suggest that the barriers to quality palliative care identified by Bradford et al., including, for example, ambiguity around language, resource issues, fragmented services, limited educational opportunities and the lack of evidence base to underpin care are, in fact, not just relevant to this part of Australia. Moreover, these could be perceived as international barriers frequently experienced as the complexity of the problems these children and their families face over protracted periods continue to challenge those providing care. Commonalities regarding strategic directions across countries also exist and include the need to increase educational opportunities and the research base, alongside development of services for children with non-malignant conditions and bereavement services.

The use of technologies in the form of telehealth seems central to future developments for children with palliative care needs in Queensland. The level of information technologies now available worldwide provide endless opportunities for improving care for children and families, when location is an issue. The research currently under way regarding telehealth in Queensland will no doubt result in important insights into the value of this approach and have implications for further developments not just of this service, but for other services further afield.

Given the similarities regarding the barriers and future direction across countries within the fledgling speciality of children’s palliative care, what is clear from the Bradford paper is the potential value of harnessing the power of continued international collaborations to enhance care for children and families. The International Children’s Palliative Care Network (ICPCN) and the established international discussion forum (PaedPallCare) are examples of forums that enable the sharing of knowledge; for example, complex symptom management, sharing resources such as established care pathways and they can also aid in working towards a stronger evidence base. The increased numbers of professionals involved in caring for children and families from across disciplines can use such collaborations positively as they continuously strive to enable realisation of the ICPCN vision. That is to ensure every child with life-limiting or life-threatening conditions and their families can receive the best quality of life and care regardless of diagnosis or where they live.

*Children in this context refers to infants, children and young people.

References
Paediatric palliative care services in Queensland: an exploration of the barriers, gaps and plans for service development

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Abstract

Background The Paediatric Palliative Care Service (PPCS) of the Royal Children's Hospital (RCH) in Brisbane was established in 2009. This service has evolved from the hospital's paediatric oncology palliative care service and works collaboratively with primary health care teams in a consultative model.

Aims With the expanded scope of caring for all children diagnosed with life-threatening conditions in mind, a forum was held in late 2009 to identify barriers and gaps and to plan for the future of the PPCS.

Design Stakeholders, including medical staff specialists (24%), nurses (32%), allied health (24%), community support group representatives (16%), corporate policy representatives (2%) and bereaved parents (2%) from South East Queensland (SEQ) were invited to attend.

Results A number of barriers were highlighted including: equity in access to services; awareness, understanding and fear associated with this work; experience of health professionals; funding and resources. A lack of respite options, the need for further education, improved collaboration and improved communication between services were identified as existing gaps.

Conclusion The forum provided an opportunity to gather expert and experienced health professionals in paediatric palliative care to discuss the issues and assist in the planning for the future direction of the PPCS. This report may provide a valuable insight for other services.

What is known about this topic

- As an emerging sub-speciality within paediatrics, internationally there is a growing body of evidence regarding issues for paediatric palliative care. However, for Australia and Queensland specifically, there is a paucity in the literature.

What this paper adds

- As a developing service in Queensland, this research was undertaken to identify the barriers and gaps in service provision for paediatric palliative care in Queensland. The paper may be of benefit for other services as a model for service development.
Keywords: palliative care, community health nursing, health services accessibility, home care services, paediatric.

Declarations

Competing interests There are no competing interests that the authors are aware of that would bias the publishing of this paper.

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Ethical approval The study was approved by the Royal Children’s Hospital and Health Service Ethics Committee (HREC/09/QRCH/121).

Guarantor NB.

Contributorship LC, NB and L-AP conceived of the study. NB, L-AP and JR did the data collection and analysis. NB drafted the manuscript. MB, HI, JM, L-AP, JR, LC and AH revised the manuscript. MB provided the statistical expertise and JR the material support. HI and AH supervised the study.

Introduction

Statewide services for paediatric palliative care are well established in only three of seven states in Australia (New South Wales, Victoria and South Australia). Geographically, Queensland is the second largest state with a population of about four million. Around 2.5 million people live in the south-east corner, one million in towns along the coast with the remainder dispersed across the state in smaller rural towns. There are two tertiary paediatric hospitals within South East Queensland (SEQ) in Brisbane, and established relationships with major regional hospitals who have either a paediatric ward or access to paediatricians. Services in regional hospitals and the community throughout Queensland are either paediatric or palliative care-focused, not both and, as a result the particular needs of a paediatric palliative care patient are not always identified.

Childhood life-threatening conditions have been broadly categorised into four groups by the Association of Children’s Palliative Care. Group 1 includes conditions which are potentially curable, such as cancer or organ failure. Group 2 consists of conditions which aren’t defined as progressive, but which require intensive treatment for complications from which a child might not recover; for example, inoperable congenital heart disease and cystic fibrosis. Group 3 are progressive conditions, which are unable to be cured. Metabolic and storage disorders such as Retts syndrome, Batten’s disease and Adrenoleucodystrophy are examples of this category. Group 4 are defined as severe neurological conditions which increase susceptibility to respiratory infections which, over time, are ultimately life-threatening.

With the aim of developing a model of care for a statewide service for Queensland, expert and clinical stakeholders in paediatric palliative care from SEQ were invited to attend a forum in November 2009. The purpose of the forum was to identify and discuss the barriers and gaps in service provision in Queensland for children requiring palliative care. A secondary aim was to foster collaboration and facilitate networking relationships. This paper presents a descriptive analysis of the barriers and gaps identified by participants at the forum, as well as suggestions for service development.

Methods

Recruitment

A purposeful strategy was used to invite health professionals and other stakeholders to participate in the forum. The aim was to maximise diversity in terms of discipline, practice location and to include bereaved parents and corporate policy representatives. Invitations were sent to hospital and community organisations in SEQ who were known to have been involved with the care of children with palliative care needs.

Sample characteristics

Ninety-six invitations were sent and 60 individuals attended on the day. Attendees were provided with a workbook upon registering and were asked to consent to having the comments from their workbook included in this article. Thirty-eight individuals (63% of attendees) consented and provided their workbook for analysis at the completion of the forum. Tertiary (65%) and regional hospitals (4%) as well as community organisations from metropolitan (22%) and regional SEQ (9%) were represented. There were several experts among the participants whose experience in paediatric palliative care extends over many years. The majority of participants (69%) were health professionals who had been involved in the care of five or more paediatric palliative care patients (Table 1). Allied health professionals in attendance included social workers, psychologists, pharmacists, music therapists and occupational therapists.

The forum

The forum was held at the Royal Children’s Hospital (RCH) in Brisbane, the major paediatric tertiary hospital in Queensland. The forum was held over one afternoon and consisted of three presentations from experts in the field, a focus group session lasting 80 minutes and a concluding discussion of the issues and themes raised during the afternoon.

The first two presentations focused on describing paediatric palliative care with definitions of the categories of childhood life-threatening conditions, illustrated with two case study examples. The final presentation explored working with dying children and their families and the concept of love and fear permeating clinical interactions.

The 13 focus groups consisted of four to five individuals and were pre-organised to mix disciplines as well as community and hospital representatives, encouraging networking and provoking thought and discussion beyond individuals’ usual areas of expertise. During the focus group, participants were asked to complete a workbook. The workbooks consisted of
a front page with instructions and a consent form. Following the front page were five blank pages with one topic question on each page: perceived barriers; perceived gaps; what families want; what is done well; and suggestions for service development. The focus groups were facilitated by the study authors and presenters who guided, but did not participate in the group sessions. Fifteen minutes was allocated to each topic for group discussion with five minutes between topics for individual documentation. Workbooks were voluntarily submitted at the conclusion of the afternoon.

Analysis
Data from the workbooks was transcribed verbatim by a research assistant and analysed for congruent subject matter by three of the study authors (NB, LP and JR). Themes were coded according to frequency and ranked from most to least reported.

Results
Major themes
Participants reported similar themes for barriers and gaps in service provision for paediatric palliative care. These barriers and gaps as well as the results of what participants remarked is done well, and what families need, are presented in Table 2.

Equity in access to services
Access to services was reported as the most obstructive barrier to quality care. Access to any palliative care service for people in rural and remote areas is a significant barrier. The majority of services and experienced clinicians are concentrated around SEQ; therefore, families living in regional, rural and remote parts of Queensland are required to travel, at times great distances, to attend specialists’ appointments. One participant commented, “What you can access is very much dependent on [a] patient’s postcode due to the funding model, as well as experience and confidence of staff in service”.

It is not only the geography of Queensland that impedes access, but also diagnosis. For children with an oncological diagnosis there is an established service through the RCH which includes 24/7 toll-free telephone support and a network of nursing coordinators in all major regional centres. For children with a non-oncological diagnosis there is no such support. It was suggested that, as a group, oncological diseases have a louder ‘voice’ and receive more social recognition and compassion than other childhood life-threatening conditions. Participants commented that, “Children with an oncological diagnosis receive better access to palliative care services” and that “Chronic [non oncological] conditions are under-resourced”.

The inequity that exists in services being provided according to diagnosis rather than need can be attributed to the awareness and understanding towards childhood life-threatening conditions, not only as health professionals, but as a society. The concept of awareness, understanding and fear were the second most reported obstacles.

Awareness, understanding and fear
It was reported that awareness and understanding influenced the attitudes of families and communities and clinicians’ tendency to refer to appropriate services. One participant stated there can be a “... refusal to acknowledge [the] need for palliative care expertise” by clinicians. The concept of fear pervaded comments as a barrier, both from the families and clinicians’ perspectives. Participants reported, “it’s a very difficult conversation to have with parents” and there is a “fear of knowing what to say”.

From a societal viewpoint, it was suggested that there is an “aversion to the idea that there’s a need for paediatric palliative care”. In our culture the expectation is that medicine should have the ability to cure. It was suggested there is a negative perception of the word palliative; “fear it is giving up hope”, “the word palliative changes relationships”, “fear of being abandoned”.

As a result of paediatric palliative care needs not being widely recognised in the community, issues regarding funding and resource allocation arise.

Funding and resources
The funding model that exists is adult-focused, limited to three months and described by a participant as “... insufficient to meet service needs such as nursing, equipment and respite”. It was reported there is pressure on services to provide ongoing services and the lack of funding impedes the ability to maintain care. Families caring for a child with complex health needs face financial burdens due to loss of income and increased medical and travel expenditure.

Table 1. Summary of consenting participants’ discipline and speciality area.

<table>
<thead>
<tr>
<th>Discipline</th>
<th>Paediatric oncology</th>
<th>Paediatrics</th>
<th>Palliative care*</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing</td>
<td>3</td>
<td>8</td>
<td>4</td>
<td>15</td>
</tr>
<tr>
<td>Allied health</td>
<td>2</td>
<td>5</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Management</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Medical</td>
<td>1</td>
<td>3</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>Parent</td>
<td></td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Pastoral care</td>
<td></td>
<td>2</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Support group</td>
<td></td>
<td>2</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>TOTAL</td>
<td>6</td>
<td>22</td>
<td>8</td>
<td>38</td>
</tr>
</tbody>
</table>

*Adult-focused
Whilst some families receive a ‘package’, which includes financial assistance from state and federal agencies, there were suggestions that funding is not equitable across the spectrum of life-threatening conditions affecting children.

Funding was reported to be an issue for the many non-government organisations that families rely upon. With changes in the economic climate, charitable organisations that rely upon the support of the community have seen a reduction in donations as well as a devaluation of assets. This has resulted in reduced income and fewer available resources to support families.

**Respite**

The need for respite care is vital if a parent is to sustain the intense level of care that is required during palliative care. Unfortunately, due to administrative and funding issues, Brisbane’s only dedicated children’s hospice was forced to close in July 2009. Consequently there is no respite facility for families currently available in Brisbane.

Participants at the forum felt the lack of a paediatric facility or services to provide respite was a major gap. One participant commented, ‘... families want night and weekend respite most urgently and this is the hardest respite to get’. The importance of appropriately trained personnel to provide the respite was discussed, ‘... there is a requirement for a service that is professionally run with people who know what they are doing’. Respite in the form of domestic assistance was also a reported gap.

**Lack of other services for paediatric palliative care**

The compounding effect of the barriers and gaps as discussed raises the issue of the lack of services. The most reported service lacking was that of after-hours support. Particularly on weekends and public holidays, the availability of a telephone support service for children with non-oncological, life-threatening conditions was reported as a significant gap.

In general it was reported that the system is more reactive than proactive and that potential reduction in stress and suffering could be achieved with improved counselling and bereavement support.

**Coordination of care**

Fragmentation of care can occur when many consulting teams are involved. Teams do not always communicate effectively, affecting coordination of care. One participant highlighted this, ‘... families are requested to come to hospital four times per week for out-patient appointments’. The suggestion was made that:

> ... one person needs to be the key worker to coordinate supports and services. This key person needs to be accessible for families and communities services alike.

It was suggested that, ‘... territorial attitudes and ownership of clients and families’ affected coordination with tertiary teams and/or individual clinicians unwilling to refer back to primary teams. It was acknowledged that it is ‘difficult for all concerned ... the lines [are] often blurred. When does active care end and what is the role of the support systems?’

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### Table 2. Summary of major themes, frequency of occurrence (with percentages) as ranked by participants (n=38).

<table>
<thead>
<tr>
<th>Theme</th>
<th>Occurrence</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Barriers and gaps</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Equity in access</td>
<td>35 (85.5%)</td>
<td>1</td>
</tr>
<tr>
<td>Awareness, understanding and fear</td>
<td>28 (70%)</td>
<td>2</td>
</tr>
<tr>
<td>Funding and resources</td>
<td>27 (67.5%)</td>
<td>3</td>
</tr>
<tr>
<td>Lack of respite</td>
<td>27 (65.5%)</td>
<td>4</td>
</tr>
<tr>
<td>Lack of clinicians’ experience in paediatric palliative care</td>
<td>24 (60%)</td>
<td>5</td>
</tr>
<tr>
<td>Lack of services</td>
<td>23 (57.5%)</td>
<td>6</td>
</tr>
<tr>
<td>Coordination of care</td>
<td>23 (57.5%)</td>
<td>7</td>
</tr>
<tr>
<td><strong>What families need</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respite</td>
<td>25 (62%)</td>
<td>1</td>
</tr>
<tr>
<td>Compassionate communication</td>
<td>24 (60%)</td>
<td>2</td>
</tr>
<tr>
<td>Continuity of care/case management</td>
<td>21(52.5%)</td>
<td>3</td>
</tr>
<tr>
<td>After-hours support</td>
<td>16 (40%)</td>
<td>4</td>
</tr>
<tr>
<td>Financial support</td>
<td>18 (45%)</td>
<td>5</td>
</tr>
<tr>
<td>Practical assistance</td>
<td>13 (32.5%)</td>
<td>6</td>
</tr>
<tr>
<td>Choice and flexibility</td>
<td>11 (27.5%)</td>
<td>7</td>
</tr>
<tr>
<td>What is done well</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Holistic approach</td>
<td>20 (50%)</td>
<td>1</td>
</tr>
<tr>
<td>Case conferencing between teams</td>
<td>17 (42.5)</td>
<td>2</td>
</tr>
<tr>
<td>Utilising local communities to support families</td>
<td>8 (20%)</td>
<td>3</td>
</tr>
<tr>
<td>After-hours support for oncology families</td>
<td>8 (20%)</td>
<td>4</td>
</tr>
<tr>
<td>Increasing use of technology</td>
<td>7 (17.5%)</td>
<td>5</td>
</tr>
<tr>
<td><strong>The future – suggestion to develop the service</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>22 (55%)</td>
<td>1</td>
</tr>
<tr>
<td>Development of statewide model</td>
<td>22 (55%)</td>
<td>2</td>
</tr>
<tr>
<td>Improve collaboration</td>
<td>19 (47.5%)</td>
<td>3</td>
</tr>
<tr>
<td>Research</td>
<td>10 (25%)</td>
<td>4</td>
</tr>
<tr>
<td>Formal bereavement programme</td>
<td>6 (15%)</td>
<td>5</td>
</tr>
</tbody>
</table>
care end and palliative care begin?” This uncertainty may confuse goals of care and delay the initiation of support and respite from suffering that the palliative approach could offer.

It was also reported that there is a lack of awareness of what services are available, that services do not collaborate and that duplication of services exists, tying up funds in administration and bureaucracy. One participant made the observation that, “… there is no universal and accessible service across Queensland to support these families”.

**Lack of clinicians experienced in paediatric palliative care**

Due to the geographical size of Queensland, it is impossible to know where and when a service, be it a general practitioner (GP), community nursing organisation or small rural hospital, might be required to care for a child with a life-threatening condition. As one participant commented, “[there is] lack of confidence in the ability to provide services to children which is particularly difficult in rural areas where there is inadequate education”.

From the viewpoint of a clinician inexperienced in paediatric palliative care, this lack of confidence results in “fear and awkwardness” and reluctance to “get involved”. An example was given of community nursing agencies refusing referrals on the basis of not feeling confident to provide services.

Community service representatives reported the lack of an integrated model between acute and community settings as a potential reason for refusing referrals. It was suggested that support is required to effectively bridge the gap and manage the care plan. It should not be assumed by the referring hospital team that the community team will be familiar with terminology, medication dosing and interventions that are specific to the complex needs of an individual patient.

**Suggestions for developing the PPCS**

Education and training in paediatric palliative care has been identified as a priority for ensuring high-quality care is available8,13,14. Aligning with these findings, increased educational opportunities, especially for those from regional and remote areas were felt to be the most important action for the PPCS to undertake. Regular educational forums and other opportunities for clinicians including GPs, to extend their skills and awareness of the particular needs of families caring for a child with a life-threatening condition were suggested.

The development of a statewide model that would streamline and trigger referrals and provide a platform for coordinating and communicating between services was felt to be conducive for facilitating education, strengthening networks and ensuring equity of service provision. Other suggestions for the PPCS included research to build on the evidence base, a formal bereavement programme, formalised care plans and end-of-life pathways, improved community resources and supports (such as in home respite, equipment and domestic assistance) and a paediatric hospice for respite care.

Following the forum, these suggestions were incorporated into planning for the development of the PPCS. It is anticipated that in 2014, the two tertiary paediatric hospitals in Brisbane will be merged into one facility: the Queensland Children’s Hospital. A comprehensive five-year strategic plan has therefore been developed to carry the PPCS through this merger, with a model of care that remains consultative and supportive of primary treating teams. Key elements of the strategic plan have commenced:

- A bereavement coordinator has been appointed to develop a statewide programme to support families and the health care professionals that care for them.
- A series of educational workshops for nurses was developed and run in-house to gain feedback. It is planned to make these workshops available online, in the form of presentations that could be accessed throughout the state.
- In the meantime, videoconferencing has been successfully used to deliver in-services on specific conditions to regional areas. These in-services generally precede discharge videoconferences, which are now used routinely for all children referred to the service on returning home to regional and remote areas.
- A programme of online health within the home has also been established. It is anticipated that using telehealth routinely in this manner may improved communication and coordination between services and a research study is underway to evaluate this. As well as research in telehealth, surveys have been developed on respite and bereavement needs of families.

The PPCS has also welcomed the opportunity to present on a variety of palliative care issues at conferences and meetings, grand rounds and regional workshops to medical nursing and allied health professionals from all parts of Australia.

Ongoing work in service mapping and networking continues to develop the knowledge of services and lack thereof throughout Queensland. Participating in benchmarking with other paediatric palliative care services has also been a priority in ensuring the development of the service is aligned with national standards.

**Discussion**

It is acknowledged in the literature that there are distinct differences between paediatric and adult palliative care6. The principal difference is the difficulty of prognostication in relation to the timing and possible outcomes across the different spectrums of childhood life-threatening conditions13,15. Many children have long disease trajectories and, with advances in supportive care, some patients are even surviving into young adulthood with complex health needs16. At the same time, at any moment these children could have an acute deterioration and die. This raises difficulties with the provision of services and government funding17. While the number of children who require palliative care is much smaller than the number of adults, care for a child may involve provision over many years with increasing complexity18. Additionally, the needs of the whole family unit need to be addressed with attention to parents, siblings and grandparents as well as the child’s community, which includes school. As a consequence of there being a small
number of children who require palliative care, there are also only a small number of clinicians skilled in managing the specific physical, emotional and spiritual needs that are experienced during a child palliative phase.

There are unique vulnerabilities and risks associated with the provision of paediatric palliative care and it is critical to be able to provide age-appropriate services and support. In 2000 a report by Crowe highlighted issues regarding paediatric palliative care in Queensland and it is notable in the 10 years since that report, many of these issues were reported as an ongoing concern at the forum. This suggests that little progress has been made.

One possible reason for this is that childhood death is not a usual occurrence in society. In developed countries, the death of a child is rarely encountered by the average person. This results in a lack of awareness and understanding of the surrounding issues. Many clinicians and families believe palliative care is only end-of-life care and a referral to palliative care infers death is imminent. The continued hope for survival by both parents and clinicians, coupled with the prognostic uncertainty of many childhood life-threatening conditions, makes it, therefore, very challenging to refer to palliative care services.

Research suggests early recognition of a poor prognosis and the introduction of palliative care while still maintaining hope results in optimal care. The concept that palliative care and good paediatric care can co-exist with the same goals, regardless of outcomes, needs to be integrated into practice. Education is required to inform clinicians and communities in general to clarify understanding of what palliative care is.

There is a need for greater understanding of how to control physical and psychological symptoms, how to communicate with children, how to ensure suffering is not prolonged in the quest for living and how to care for bereaved families. Work needs to be done to address the significant barriers and gaps described above and further research is required to inform clinicians and design supportive public policies. It is hoped that the development of the PPCS will lessen the width of these gaps and, through collaboration and education, decrease the barriers within Queensland.

Limitations

The participants at the forum were health professionals and individual stakeholders in paediatric palliative care from SEQ. It is acknowledged that there were no representatives from the rest of the state of Queensland. The group presentations and discussions may have influenced participants' individual opinion that was recorded in their workbooks and, therefore, this analysis.

Conclusion

The forum provided the opportunity for stakeholders in paediatric palliative care to meet as a group to discuss and define the issues relating to paediatric palliative care in Queensland, generating an agenda on which to collectively act upon. Analysis of the themes identified major issues for paediatric palliative care and suggested areas for developing the scope of the PPCS to meet the needs of children living in Queensland diagnosed with a life-threatening condition. The results from the forum have been included in the strategic plan for the future direction of the PPCS and have contributed to the collective understanding of the barriers and gaps in service for paediatric palliative care in Queensland. There are always opportunities to improve the quality of the care we provide to our patients and through the forum we were able to gain a valuable insight in to where our efforts should be focused. It is hoped that this process and the presented results are useful to other developing services.

Acknowledgements

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References


The ventilator-dependent infant requiring palliative care in the neonatal intensive care unit: a literature review

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Abstract

Aim To review the literature relevant to palliative care of the ventilated infant and their family.

Background Impeccable symptom assessment and management is necessary to ensure the optimal quality of life for the ventilated palliative infant and their family. There is a plethora of literature regarding symptom assessment and care when a decision has been made to withdraw ventilatory support. However, there is a lack of literature related to nursing practice for the palliated infant who remains dependent upon ventilatory support until death.

Data sources CINAHL, PubMed, Elsevier and Proquest Health and Medical Complete databases were searched (2000–2009).

Methods Seventeen articles were reviewed including: 10 research reports; three literature reviews; two discussion papers; one systematic review and one report documenting the development of a paediatric palliative care programme.

Results Best practice palliative care requires that care be planned and implemented by an expert multidisciplinary team in collaboration with the infant’s parents who should participate in all levels of decision making to ensure optimal care. The need for impeccable symptom assessment was identified as a key factor in the provision of high-quality symptom control. The assumption regarding a paucity of literature surrounding the continuation of family-centred palliative care for those infants who remain on a ventilator until their death was supported.

Conclusion and relevance to clinical practice Evidence-based recommendations highlighted in this review may be used as a starting point to formulate neonatal intensive care unit (NICU) clinical guidelines for family-centred palliative care of the ventilator-dependent infant.

Keywords: neonates, infants, dying, neonate/adj/units, nursing care, end-of-life care, palliative care and neonatal palliative care.

What is known about this topic

• The key elements of care required by the palliated and ventilated infant prior to, and including, the withdrawal of treatment and subsequent bereavement should include: pharmacological and non-pharmacological management; a family-centred approach to care; and that care should be led by a multidisciplinary team, preferably in conjunction with a palliative care team.

• There is a lack of clinical guidelines to support optimal nursing care of the ventilated palliative infant who remains ventilated until death occurs.

What this paper adds

• A review of recommendations from the literature between 2000 and 2009 for the palliative care of ventilated infants.

• Confirmation of a gap in the literature pertaining to the care of ventilated palliative infants.

• Motivation to focus on the needs of this small but important group of infants and plan specific research that can provide rigorous evidence to support improved care initiatives.
Declarations

Competing interests nil
Funding nil
Ethical approval not required
Guarantor CF
Contributions Conception of study, wrote and edited manuscript CF. Supervision and revision of manuscript LM.

Introduction

There are a small number of infants who are dependent on mechanical ventilatory support and whose care is deemed palliative. The goals for successful palliative care for such infants are to recognise and treat physical symptoms such as pain, increased work of breathing and seizures and to provide psychosocial, cultural and spiritual support in the best interests of the dying infant and their family. By following these principles of care, the infant is best placed to experience a humane and dignified death\(^1\).\(^2\). Withdrawal of ventilatory support and family bereavement care are important components of care for the dying infant and there is an abundance of literature surrounding these issues. However, literature related to the assessment of needs and recommendations for optimal family-centered palliative care for infants remaining on a ventilator until death is lacking\(^3\). Further, there are no published guidelines to support nurses caring for this specific and vulnerable population of infants and their families.

Objective

The objective of this literature review was to identify the key components for delivery of optimal care for the infant requiring palliative care who remains ventilated until death occurs. It is anticipated these key components may be used by nurses to develop evidence-based clinical recommendations for ventilated neonatal palliative care.

Aims

To review scholarly-based literature surrounding palliative care of the ventilated infant to determine:

1. The infant’s palliative care needs.
2. The function of the multidisciplinary team in promoting optimal palliative care of the ventilated infant in NICU.
3. The physical, psychosocial and cultural needs of the palliative infant’s parents and family.

Methods

OvidSP Universal Search was used as the search engine for the following electronic databases: CINAHL, PubMed, Elsevier and Proquest Health and Medical Complete. A Boolean operated and adjacency search method was used to limit the search to papers relating specifically to the target population of ventilated infants requiring family-centred palliative care. The Cochrane and Joanna Briggs libraries were also searched but no relevant literature was accessed. The limits of the search included papers published since 2000 in the English language that were considered scholarly- and journal-based. The following search terms were used: ‘neonates’; ‘infants’; ‘dying’; ‘neonate/adj/units’; ‘nursing care’; ‘end-of-life care’; ‘palliative care’ and ‘neonatal palliative care’.

The following criteria were used to select manuscripts to be reviewed: palliative care and ventilated infants within a neonatal intensive care unit (NICU). Twenty-four full text articles were found and 17 were identified as being relevant. These included: 10 research reports, three literature reviews, two discussion papers, one systematic review and one programme development report. After close scrutiny seven articles\(^4\)\(^-\)\(^10\) were excluded as they focused on paediatric palliative care (n=3) and neonatal nurses’ experience of caring for dying infants (n=4).

<table>
<thead>
<tr>
<th>Strength/grade of recommendation</th>
<th>Level of evidence</th>
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<tr>
<td>A</td>
<td>The evidence is patient-related and is of a good quality and consistency.</td>
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<tr>
<td>B</td>
<td>The evidence is patient-related and is of a lower quality and is inconsistent.</td>
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<tr>
<td>C</td>
<td>The recommendation involves evidence from usual practice, opinion, consensus and case series for studies. Disease-oriented evidence.</td>
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<tr>
<th>Level of evidence</th>
<th>Type of study</th>
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<tr>
<td>1 <em>High-quality patient-orientated</em></td>
<td>Systematic review/meta-analysis of randomised control trials with consistent findings.</td>
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<tr>
<td></td>
<td>High-quality individual randomised control trial.</td>
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<td></td>
<td>High-quality cohort study with good follow-up (&gt;80%).</td>
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<td></td>
<td>Lower quality clinical trial.</td>
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<td></td>
<td>Lower quality cohort study.</td>
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<td></td>
<td>Case-control study.</td>
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<tr>
<td>3 <em>Other evidence</em></td>
<td>Opinions, usual practice, consensus, disease-oriented evidence and case-control study.</td>
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Table 2. Studies retrieved but not selected.

<table>
<thead>
<tr>
<th>Author</th>
<th>Reason for exclusion</th>
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<tr>
<td>Knapp C et al.</td>
<td>Setting was paediatric palliative care.</td>
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<tr>
<td>(2008)</td>
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<tr>
<td>Meyer E et al.</td>
<td>Setting was paediatric palliative care.</td>
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<tr>
<td>(2008)</td>
<td></td>
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<tr>
<td>Kain V</td>
<td>Literature review exploring moral distress in neonatal nurses caring for dying infants.</td>
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<tr>
<td>(2007)</td>
<td></td>
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<tr>
<td>Caitlin A et al.</td>
<td>Study report exploring moral distress and conscientious objection as a response to orders causing suffering at end-of-life.</td>
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<tr>
<td>(2008)</td>
<td></td>
</tr>
<tr>
<td>Rogers S et al.</td>
<td>Study exploring impact of an educational intervention to reduce moral distress in neonatal nurses caring for dying infants.</td>
</tr>
<tr>
<td>(2008)</td>
<td></td>
</tr>
<tr>
<td>Rini A, Loriz L</td>
<td>Setting was paediatric palliative care.</td>
</tr>
<tr>
<td>(2007)</td>
<td></td>
</tr>
<tr>
<td>Akpinar M et al.</td>
<td>Outcome measured was Turkish intensive care nurses’ attitude to end-of-life decisions.</td>
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<tr>
<td>(2009)</td>
<td></td>
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The Strength of Recommendation Taxonomy (SORT)\(^{11}\) was used as the method of grading each manuscript (Table 1). This taxonomy comprises two grading scales: a) the strength/grade of the recommendation and b) the level of evidence. All manuscripts were allocated a SORT grade of C and either 2 or 3 for the level of evidence. All scores were low and indicate a lack of high-quality empirical evidence for making recommendations for evidence-based practice, demonstrating the need for further research.

This search revealed a lack of literature that specifically identified and addressed care for ventilator-dependent infants who are deemed palliative and remain on ventilatory support until death occurs. Therefore, care leading up to withdrawal of support dominates this review. Bereavement care, whilst an important aspect of palliative care, will not feature in this paper.

**Results**

Seventeen articles that met the inclusion criteria were retrieved (Table 3). Twelve\(^{1,3,12-20}\) of these papers related to the palliative needs of ventilated infants and some also focused on the role of multidisciplinary teams and issues facing these parents. However, Davidson and colleagues\(^{21}\) and Engler and colleagues\(^{22}\) were two identified studies relating to parents of ventilated infants requiring palliative care, and did not address palliative care needs of the ventilated infant. Although the article by Sepulveda and colleagues\(^{23}\) does not relate directly to the practical aspects of palliative care of ventilated infants it was included because it was considered relevant as a discussion paper on the World Health Organization’s (WHO) view and definition of optimal palliative care for children. In addition, while the study by Partridge and Wall\(^{24}\) was published outside the time limits set for the review, it was included because it is highly cited by the authors whose papers were included in this literature review. The same was decided for the work by authors Blackburn and Vandenberg\(^{25}\), cited by Walden and colleagues\(^{17}\) and renowned for their contributions to developmental care of the infant.

Information from the studies relating to this literature review was organised and reviewed under the following relevant topics: palliative care needs for ventilated infants; the function of the multidisciplinary team in promoting optimal palliative care for the ventilated infant; and identifying and providing support for the parents of ventilator-dependent infants who require palliative care in the NICU.

**Palliative care needs for ventilated infants**

**Defining palliative care for children**

In 1998 the WHO\(^{26}\) defined palliative care for children as:

> ...actively caring for all aspects of the child and family to improve quality of life when diagnosis indicates a life-threatening illness. It begins when diagnosed, and continues whether or not the child is actively treated for the illness.

Effective palliative care involves the prevention and relief from symptoms by scrupulous assessment, early detection and treatment of pain and other physical problems as well as managing spiritual, psychological and social distress. Sometimes interventions may be deemed necessary to assess and prevent potential causes of worsening symptoms. The WHO recommends a multidisciplinary and family-centred approach to assessing the needs of the child and family, helping them make intervention and treatment decisions that provide optimal palliative care\(^{23,26}\).

**Pharmacological management**

Pain receptors are fully developed by 30–37 weeks’ gestational
Table 3. Summary of literature relevant to the palliative care of the ventilator infant and family.

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Overall objective</th>
<th>Design</th>
<th>Findings</th>
<th>Limitations</th>
<th>SORT/level of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Matthews et al. (2008)</td>
<td>To explore the influence of weight on receiving comfort medication in the four hours prior to ventilator withdrawal.</td>
<td>Retrospective chart review.</td>
<td>&gt;1500 g more likely to receive than the 800 g–1500 g. &lt;800 g significantly less likely. Weight not a true reflection of gestation (e.g. severe oedema). Cause of death confounding results (e.g. NEC infants may be more likely to receive comfort medication). Lack of palliative care programmes. Pain management primary concern for parents. Nurses are in a prime position to assess pain.</td>
<td>Focused on comfort medication received by the infant for withdrawal of the ventilator.</td>
<td>C/2</td>
</tr>
<tr>
<td>Catlin A, Carter B (2002)</td>
<td>A protocol to appropriately fulfill the needs of the infant with a life-limiting condition and the needs of their family and attending staff.</td>
<td>Consensus document.</td>
<td>May be a combination of curative and palliative before transitioning to complete palliative care. Transition to symptom management. Interdisciplinary team involvement. Staff education essential. Spiritual and cultural support. Give parents choices for care. Create memories.</td>
<td>Did not specify whether infants remaining on mechanical ventilation indefinitely and receiving palliative care were included.</td>
<td>C/3</td>
</tr>
<tr>
<td>Romesberg T (2007)</td>
<td>Palliative care requirements for the neonate. Identifying and meeting the challenges of a neonatal palliative care programme.</td>
<td>Literature review</td>
<td>Neonatal palliative care may be a combination of curative and palliative or may alternate between the two. Take notice when parents express concern about pain. Aim for families to remain intact and functional as much as possible. Palliative care teams save resources. Importance of culturally sensitive care. Focus on palliative care education. Assist and support parents in decision making – one decision at a time.</td>
<td>Limited description of palliative care for the ventilated infant.</td>
<td>C/3</td>
</tr>
<tr>
<td>Kostelanez A, Dhanireddy R (2004)</td>
<td>A review to determine the effect advances in neonatal practice in the last decade have had on the outcome of very low birthweight infants following CPR in NICU.</td>
<td>Retrospective chart review</td>
<td>Poor outcome for those infants who have lethal conditions and receive CPR.</td>
<td>Focused on CPR outcome for ventilated infants.</td>
<td>C/3</td>
</tr>
<tr>
<td>De Lisle-Porter M, Podruchny A (2009)</td>
<td>An end-of-life care guideline.</td>
<td>Literature review</td>
<td>Overview of care of infant and family. Bereavement care strongly features in NICU policies. Palliative care features much less. Limited education available. Parental involvement in decision making to withdraw has increased. Parental grief discussion. Identified factors influencing the decision. Coping abilities are affected; therefore, decisions should be in conjunction with the MDT for advice and information.</td>
<td>Focused on discontinuation of ventilation. No specific pharmacological recommendations.</td>
<td>C/3</td>
</tr>
<tr>
<td>Author (year)</td>
<td>Overall objective</td>
<td>Design</td>
<td>Findings</td>
<td>Limitations</td>
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<tr>
<td>Pierucci R et al. (2001)</td>
<td>To describe end-of-life care and the impact of a palliative care service.</td>
<td>Retrospective chart review.</td>
<td>Infants and their families receiving palliative care service increased from 5% in 1994 to 38% in 1997. Those infants had fewer days in ICU and fewer interventions and more support referrals. CPR was performed on more palliative infants who did not have a palliative care consultation than those who did. Documentation of discussions is better with a palliative care consultation. Some infants died whilst under the effect of paralytic drugs.</td>
<td>Focused on advocating for a palliative care service.</td>
<td>C/2</td>
</tr>
<tr>
<td>Lundqvist A et al. (2003)</td>
<td>Investigation of Swedish neonatal end-of-life practice before birth, at birth, during dying and after death.</td>
<td>Questionnaire.</td>
<td>Describes importance of place of death, support for family, bereavement care. Parents involved in care and decision making. Recommends further research on practical aspects of palliative care teams. Fifty per cent of units describe the seriously ill neonate to the parents prior to first visit.</td>
<td>Main focus was on parents.</td>
<td>C/3</td>
</tr>
<tr>
<td>Gale G, Brooks A (2006)</td>
<td>Implementation of a protocol for neonatal end-of-life palliative care with an NICU team approach.</td>
<td>Clinical programme development report.</td>
<td>Providing aggressive care for infants with a restricted life expectancy or those who are incompatible with life may be more of a burden than a benefit Care with team approach. Focus on pain relief and symptomatic comfort care. Sensitivity for cultural, spiritual and family/individual cultural beliefs and practices. Did not specify those infants remaining on mechanical ventilation and receiving palliative care.</td>
<td></td>
<td>C/3</td>
</tr>
<tr>
<td>Walther F (2005)</td>
<td>To explore different countries’ perspective of best practice for palliative care in the NICU and to present the Netherlands point of view.</td>
<td>EURONIC study group</td>
<td>Three strategies of care: Continue but do not increase treatment. Withhold emergency interventions. Withhold intensive care (i.e. withdrawal of ventilation). Brief outline of comfort care, pain relief and ethical issues.</td>
<td>Focused mainly on ethical decision making to withdraw or withhold treatment. No discussion regarding continuing treatment without increasing the intensity.</td>
<td>C/3</td>
</tr>
<tr>
<td>Walden M et al. (2001)</td>
<td>To discuss pain relief and comfort to improve end-of-life care for those infants whose life-sustaining treatment has been unsuccessful.</td>
<td>Discussion Paper.</td>
<td>Very little is known about optimal end-of-life care for infants where intensive care and treatment have failed. Need to be skilled at continuously assessing needs. Discusses physical comfort in great detail, demonstrates same with a case example. Recognises limited pharmacological strategies within the literature. Recommends MDT with a partnership approach with parents.</td>
<td>Referred to withdrawal of life support at end-of-life. Unclear whether referring to the end-point or the period entering the palliative phase.</td>
<td>C/3</td>
</tr>
<tr>
<td>Author (year)</td>
<td>Overall objective</td>
<td>Design</td>
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<tr>
<td>Moro T et al. (2006)</td>
<td>A synopsis of palliative and end-of-life care for neonates.</td>
<td>Literature review.</td>
<td>Prognosis for extremely preterm infants is often uncertain, making initiating palliative care very difficult. The majority of neonates who die do so in hospital. Palliative care includes: pain and symptom relief; meeting psychosocial, emotional and spiritual requirements. Advises that pharmacological care is found elsewhere and refers to an article on procedural pain management. The understanding of pain and symptom management is suboptimal in neonates. Parents need to be fully informed and able to accept their infant will not survive for the parent to be able to make end-of-life decisions.</td>
<td>Palliative care is methodically listed but not discussed in detail. Main focus on withdrawal of treatment (of mechanical ventilation) and withholding treatment (CPR).</td>
<td>C/3</td>
</tr>
<tr>
<td>Abe N et al. (2001)</td>
<td>To explore the process of withdrawal of mechanical ventilation in NICU.</td>
<td>Retrospective chart review.</td>
<td>Twenty-two per cent (n=18) charts had no written order for ventilator removal. Two-thirds were receiving pain relief medication at the time of removal. Eighty-three per cent had documentation regarding parental participation during removal. Most had documented support from family or chaplaincy. None had documented evidence of nursing support for families. Death was not hastened by the provision of pain relief. None had DNR orders documented. Sixty-six per cent were receiving dopamine at time of removal. Thirty-six per cent continued on their dopamine at time of removal which raises blood pressure and stimulates cardiac action. Some infants were ordered for removal of IVs at time of ventilator removal which did not allow for delay in the infant's death and provision for further symptomatic treatment.</td>
<td>Focused on the documentation for withdrawal as well as the support provided to families. Discussed pain relief medication for the infant when withdrawing ventilation.</td>
<td>C/2</td>
</tr>
<tr>
<td>Monterosso L et al. (2005)</td>
<td>The NICU nurse's view of their responsibility to contribute to ethical decisions, infant advocacy and complex clinical problem solving.</td>
<td>Questionnaire.</td>
<td>Nurses felt they had lack of involvement in ethical decisions. Nurses have a significant role as the infant’s advocate. An MDT where all members are involved improves communication toward ethical decision making.</td>
<td></td>
<td>C/3</td>
</tr>
<tr>
<td>Kopelman A (2006)</td>
<td>Good communication using an MDT approach can prevent conflicts with parents.</td>
<td>Discussion paper.</td>
<td>Parent misunderstanding of the issue is the most common reason for conflicts. Checklist for communicating a poor prognosis.</td>
<td></td>
<td>C/3</td>
</tr>
<tr>
<td>Author (year)</td>
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<td>Davidson J et al. (2007)</td>
<td>The development of guidelines for the support of the patient and family in the adult, paediatric or neonatal ICU.</td>
<td>Systematic review.</td>
<td>Shared decision making is recommended and is achieved by: Early and frequent meetings amongst the ICU team members, and the team with the family. Individualised care. Cultural support. Clergy. Layman’s terminology. Training in facilitation of communication and conflict management.</td>
<td>Refers to adult, paediatric as well as neonatal.</td>
<td>C/3</td>
</tr>
<tr>
<td>Boss R et al. (2009)</td>
<td>To measure the preparation training undertaken by graduating neonatologists (United States) in communication and making end-of-life decisions with families.</td>
<td>Web-based national survey.</td>
<td>Substantial training in medical management of dying infants and extremely preterm infants. Inadequate training in communication and facilitating shared end-of-life decisions with families. Conflicts with staff may cause parents not to want to take part with the MDT in end-of-life decision making.</td>
<td>Refers to the families.</td>
<td>C/3</td>
</tr>
<tr>
<td>Engler A et al. (2004)</td>
<td>To explore and describe neonatal nurses’ perception of palliative care of families of extremely ill and/or dying infants.</td>
<td>Survey</td>
<td>More research required in improving end-of-life care for families. Nurses may feel they are not acting in the best interest of the dying infant when the parents are unable to consent to withdrawal of the ventilator. Appropriate education assists nurses to cope with loss of an infant in NICU. Education must include cultural awareness and sensitivity.</td>
<td>Refers to the families.</td>
<td>C/3</td>
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age\(^1\). It has been found that neonates experience greater sensitivity to pain than older children and adults\(^1\). Further, even extremely preterm infants have been found to have sufficient development to experience pain\(^24\). There was general consensus that dying infants must experience a humane and respectful death without pain or suffering\(^1,14,17,18,27\).

Pain management is a critical component of palliative care. Unfortunately there is a history of inadequate and inappropriate use of pain medication for neonates in general\(^1,12,13\). A problem sometimes encountered by NICU nurses may be the lack of venous access in the deteriorating infant. It is noteworthy this challenge was mentioned in only one article\(^17\). The authors provided scant detail on the provision of effective pain management when the route of administration is required to be altered from continuous intravenous infusion to oral or nasogastric routes when venous access is no longer possible. Also lacking in the reviewed literature were pharmacological recommendations for comfort and procedural pain management. Walden and colleagues\(^1,17,18\) did, however, recommend using the expertise of a palliative pain team to devise individual pain relief plans which should include advice for options for preventing procedural pain but gave no pharmacological detail. In addition Catlin and Carter\(^1\) recommended a planned approach to the preparation of correct doses of medications (that is, intravenous, suppository or buccal) in conjunction with pharmacy professionals. The doses should be sufficient to provide comfort and prevent signs of air hunger. These authors highlighted the need for systematic recognition, management and treatment of symptoms such as those caused by seizures\(^1\). Whilst Catlin and Carter\(^1\) recommended educating staff on the use of appropriate pain assessment tools for the newborn, several authors\(^1,17\) have highlighted there is no pain assessment tool developed specifically for neonates at end-of-life when the infants are often moribund and consequently showing few facial or behavioural cues. Walden and colleagues\(^17\) agreed there is value in monitoring using behavioural pain assessment tools specifically developed for critically ill infants, providing the infant has the ability to communicate pain according to the tool assessment criteria. It is important to note that Walden and colleagues\(^17\) emphasised sedation should only be used in combination with adequate analgesia because the sedative medications may dull the infant’s ability to demonstrate the behavioural signs associated with pain.

The literature identifies morphine and fentanyl as the most common analgesics used for providing pain control in infants. The drug protocols provided for these particular analgesics are usually written to ensure safe dosages are prescribed to prevent the adverse effect of respiratory depression. However, the dying infant may be in severe pain or have developed opioid tolerance and, therefore, require a higher dose. Use of opioids combined with anxiolytics such as benzodiazepines are recommended as an effective analgesia adjuvant to combat opioid tolerance and provide adequate pain relief\(^22\). Matthews and O’Connor-Von\(^12\) examined the use of morphine and fentanyl and the benzodiazepines lorazepam and midazolam in their study of pain and comfort management during withdrawal of ventilatory support. They found infants with a condition diagnosed as being painful and already receiving analgesics were more likely to be given opioids during the withdrawal of the ventilator than those who had not received any analgesia prior to the decision to withdraw. Abe and colleagues\(^19\) agreed, finding 88% (n=11) of infants had intravenous access removed at the same time as the withdrawal of the ventilator. In their study only 22% (n=2) of those who were already receiving a fentanyl infusion continued to receive the pain medication after withdrawal. In order to provide effective pain relief it is imperative for care givers to have confidence in administering analgesia and sedation and not to withhold or restrict administration because of fear it may precipitate death. This is supported by Abe and colleagues\(^19\) and Matthews and colleagues\(^12\), who cited Partridge and Wall’s\(^24\) study of 165 infants, demonstrating no difference in the mean dying time following withdrawal between the following three groups of infants studied: no analgesia; normal dose of analgesia; and higher than usual doses.

Many authors concur\(^1,3,14\) it is unethical to withdraw the ventilator whilst the infant is under the effect of a neuromuscular blocking agent (that is, a paralytic drug). If in use, the drug should be allowed to wear off and precise documentation is recommended to avoid misconstruing the cause of death being as a result of the effect of paralytic medication. However, Pierucci and colleagues\(^16\) found some infants had been under the effect of neuromuscular blockade during withdrawal, but surmised that death may have occurred due to sudden deterioration or a delayed parental acceptance of impending death, where the subsequent need for a hastened decision led to death whilst under the influence of neuromuscular blockade.

Nurses are key professionals responsible for the assessment of comfort and pain\(^1,12,13\). It is important they include concerns voiced by the infant’s parent in their assessment and report of these symptoms. Furthermore, listening to parents and explaining pain and discomfort assessment and management allows the parent to advocate for their infant. This approach is also valuable in the prevention of future parental regret associated with care\(^3,12\). In addition it is very important for nurses to anticipate the infant will likely experience pain or discomfort from any potentially painful or uncomfortable procedure and to plan accordingly to maximise effective palliative care\(^12,17\).

### Non-pharmacologic comfort

Non-pharmacologic comfort measures may be used as an adjunct to pharmacological intervention for the effective relief from pain and discomfort. Many authors include care that focuses on physical comfort by reducing noxious stimuli for the infant\(^1,2,14,16,17\). A noxious stimulus can be potentially or actually damaging to body tissue. Therefore, invasive and uncomfortable procedures must be avoided where possible. Investigations and treatments should not contradict the
goals of palliative care, which are to minimise discomfort and improve quality of life. Pierucci and colleagues advise the stance of “do no harm” as an effective reference point. Therefore, invasive monitoring should be ceased and care procedures should be clustered and prioritised to enhance comfort and rest. Catlin and Carter referred to recent studies that showed feeding can make breathing very difficult for these infants, thereby potentially increasing their suffering. However, it is known that in this context, feeding and hydration are controversial subjects with diverse opinions from health professionals and families and, therefore, this needs to be discussed in conjunction with the parents.

Cuddles, skin-to-skin care and breastfeeding should continue as comfort measures for the infant. In their in-depth review of NICU comfort care, Walden and colleagues highlighted the importance of optimal positioning of the infant. If unconscious, the infant will benefit most from being nursed in the supine position with the head supported and the limbs brought into the midline, whilst maintaining gentle containment using positioning aids. Alternatively the authors suggested side-lying as being helpful in enabling the infant to bring their limbs to the midline for sucking and self-regulatory measures.

Of note, whilst this type of sucking, known as non-nutritive sucking (NNS) has been shown to provide a calming and analgesic consequence, the actual mechanism is unknown and its effect seems to disappear virtually once sucking has ceased. Blass and Ciaramitaro suggest the change may be influenced by a central non-opioid mechanism given the analgesic effect is unaltered by the administration of opioid antagonists, such as naloxone or naltrexone.

In addition, Walden and colleagues recommend facilitated tucking to relieve mild pain during procedures, which involves gently flexing the infant with warm hands. They also suggest a physiotherapist consultation may further assist the parents in confidently participating in care.

The infant’s lips and mouth should be kept moistened, preventing painful drying and cracking of skin. Furthermore, the importance of the preservation of skin integrity is emphasised and the authors advise repositioning the infant two- to three-hourly as tolerated and using aids such as a gel mattress, a memory foam mattress or a sheepskin. Particular care must be taken with the extremely oedematous infant as the additional fluid in the fragile skin cells further jeopardises skin integrity and is very painful.

1. Environmental interventions

Whilst Walden and colleagues agreed no research has been conducted to empirically confirm the negative effects of light, sound and temperature on the comfort of the dying infant, they surmise from their knowledge of the infant’s nervous system and typical neurobehavioural responses that these factors can indeed have an effect. These authors cited Blackburn and Vandenberg’s proposition the visual system is very immature in the infant and focusing and fixing can be stressful prior to 28 to 30 weeks’ gestation. Therefore, Walden and colleagues advise potential discomfort and stress can be avoided by the use of simple measures such as not having an overhead light shining on the infant, shading his/her eyes during procedures and using incubator covers during rest times. In contrast, the auditory system is mature by approximately 20 weeks’ gestation and reaction to sound can be observed from approximately 24 weeks. Sudden loud noises have been linked with negative systemic effects for the NICU infant such as agitation, a rise in blood pressure and decreased oxygenation. Unfortunately the staff working in NICUs are typically the primary source of noise and may need to be reminded of the need to work in a quiet manner. Intensive care equipment and alarms add to noise levels, especially sound systems, which should not be used in the NICU because they make it difficult for the infant to discriminate their parents’ voices from the background music and talking. In general, the activity of a typical NICU can be noisy and, whilst Catlin and Carter acknowledged there may not be a choice, they advise that these infants should be nursed in a more private and comfortable area of the nursery where possible. Furthermore, these authors advise the need to discuss any movement of the infant to another area of the NICU with the family because some families have expressed feelings of isolation when moved away from an area of the NICU where they were familiar.

Finally, the infant must be assisted to maintain warmth for comfort by use of clothing and blankets when nursed in an open cot. Further steps for maintaining temperature may include nursing the infant in a warm incubator, under a radiant heat warmer and ensuring warm linen is used during procedures such as weighing infants on scales, cuddles and when covering the infant’s mattress. However, the rationale for the need to weigh an infant receiving palliative care, particularly when he/she is deteriorating, has not been considered elsewhere in the reviewed literature. This highlights the importance that all interventions be considered for their relevance and not be performed if thought the intervention will unnecessarily compromise the infant’s comfort.

2. Social care

Family interaction with the infant should be given priority and visiting should not be restricted. Romesburg went further and proposed that insertion of a tracheostomy or administration of antibiotics might be considered necessary measures to allow the parents and family more time to gather together and be with their infant. However, insertion of a tracheostomy tube as a palliative care measure was not mentioned elsewhere in the reviewed literature and this practice should be viewed with caution as it is not considered usual practice. Interaction can be further assisted by providing support for siblings during this palliative phase through the use of practical measures such as providing them with drawing materials as they may wish to draw or write a message to their infant sibling as well as the provision of food and beverages.
3. Other considerations

Several authors have recommended that orders regarding cardiopulmonary resuscitation (CPR) be clarified through discussion and decision making with the parents. In a study by Kostelanetz and Dhanireddy, it was concluded the outcome from CPR was generally considered unfavourable for those infants whose condition had progressively deteriorated and had not responded to intensive care intervention. In these situations the infant may either have a fatal congenital condition or a condition that does not respond to neonatal intensive care. The authors recommended that CPR be discussed with the parents in these circumstances and with the subsequent drafting and finalising of a ‘Do Not Resuscitate’ (DNR) order.

The function of the multidisciplinary team promoting optimal, family-centred palliative care

The multidisciplinary team (MDT) is critical to the coordination of successful care planning decisions. Individual members of the MDT are able to contribute specialised skills and knowledge that can be used in the decision-making process in conjunction with the infant’s parents. Of note is Boss and colleagues’ study suggesting graduating neonatologists felt they were poorly prepared in facilitating MDT meetings with families. This supports Walden and colleagues’ suggestion of assembling a palliative care team specifically trained in assisting parents and members of the health care team. In addition Lundquist and colleagues recommended further research be undertaken on the practical aspects of palliative care teams for neonates. Whilst Pierucci and colleagues advocated using palliative care teams, they stated that using a multidisciplinary team approach effectively resulted in a reduction in: days spent in NICU; invasive investigations; days spent tube feeding; use of medications such as inotropes and paralytics; performance of x-rays; CPR; and mechanical ventilation.

Advances in neonatal medicine have made it difficult for the general public to develop sufficient knowledge and experience to make the type of decisions required in these situations without adequate professional assistance. MDT meetings that include the family provide an opportunity for the family to be supported and to verbalise concerns and wishes for their infant’s care. It is also possible where conflicts can be addressed, defused and mediated, hence preventing conflicts between the family and staff as the family have a share in the decision making and goal setting.

The MDT for infants should consist of at least a physician, nurse, social worker and spiritual adviser. Physical, psychosocial, cultural and spiritual support are required and no one person can provide support in all aspects effectively. Monterosso and colleagues emphasised the importance of the infant’s allocated nurse, as the sole health professional to provide 24-hour care, to participate in the MDT meeting and advocate for the infant and family. Davidson and colleagues recommended holding a MDT meeting within 24 to 48 hours after an infant’s admission. Given the large number of infants usually cared for in an NICU, this would be difficult to achieve. We conclude that Davidson and colleagues may have been referring to adult and paediatric patients and the critically ill infant, rather than the palliated patient. These authors also recommended holding MDT meetings as often as required, depending on the condition of the patient in order to update information and decisions with parents using appropriate language and an interpreter as appropriate in a culturally and spiritually sensitive manner. They also suggest that improved communication may facilitate advanced directives such as DNR orders.

Identifying and providing support for the parents of ventilator-dependent infants who require palliative care in the NICU

Several authors have advocated the need for staff education focused on the provision of appropriate support for parents during the infant’s palliative care phase. Education should centre on cultural awareness and cultural sensitivity, including information and strategies to deal with cultural and language barriers.

Health care professionals are held responsible for supporting parents in their grieving process to avoid complicated grief. This support should extend to shared decision making as well as the encouragement for attachment of parents and their infants and the expression of their feelings. Nurses are in a prime position to provide such support because they are at the cot side constantly and in communication with the family. This gives the nurse the opportunity to support the parents by assessing their needs and then assisting them to articulate their concerns and wishes. In addition, the nurse also has the opportunity to offer more practical support by explaining the purpose and function of the equipment used to care for their infant and providing information about the infant’s physical appearance and their comfort level.

Pierucci and colleagues, while advocating use of the MDT model, also recommend the use of the palliative care team. They surmised that despite the WHO’s current palliative care policy recommending early involvement of the palliative and supportive care approach, some health professionals lack a clear understanding of the definition of palliative care and may think it refers to terminal care in the end-stage of life. This lack of understanding poses challenges in offering access to a palliative care service. Romesberg and Davidson and colleagues also proposed the use of an MDT approach for care planning in liaison with the palliative care team. They concurred with Pierucci and colleagues that a spiritual advisor, chaplain and/or social worker can all play an important supportive role by exploring and advocating the needs of the individual families. They also emphasised the need for consistency of information given to the parents.

Lundqvist and colleagues emphasised that care could be more meaningful for parents by encouraging them to touch, hold and care for their infant and allowing extended family and friends to visit with them and with their infant. Of note,
91\% (n=29) of the Swedish units studied encouraged parents to participate in care, including tube feeding. Davidson and colleagues\textsuperscript{21} recommended teaching parents coping strategies and stress management, as well as diary writing and offering a parent support group.

Walther\textsuperscript{16} suggested care should be provided in a comfortable and quiet room where family and siblings can cuddle their infant and share quality time. Pierruci and colleagues\textsuperscript{14} proposed it should not be within the intensive care area, whilst De Lisle-Porter and Podruchny\textsuperscript{1} say the location is unimportant as long as there is privacy and comfort provided for the family, with the staff being respectfully quiet and with lights dimmed.

Discussion
This review has identified and explored the key issues to be considered when providing palliative care for ventilated infants nursed in an NICU and caring for their families. These key issues were discussed under the major headings of pharmacological and non-pharmacological comfort measures and refer to the physical, environmental, psychosocial, spiritual and cultural aspects of family-centred care. In addition, it has been shown that MDTs can effectively facilitate shared decision making with parents by promoting good communication and providing ready access to the diverse range of health care professionals. Furthermore, it was found that palliative care teams are increasingly recognised as being an essential component of care planning to ensure the comfort of the infant, while maintaining optimal quality of life for the infant and family.

A particularly significant finding was the evidence indicating neonatal pain receptors are more sensitive than those of adults and older children, and particular care is required to ensure the prescribing of analgesia and sedation is appropriate to developmental age\textsuperscript{1}.

The literature also revealed a range of strategies for promoting family-centred care of the infant in NICU, such as keeping interventions to a minimum; monitoring and preventing possible ill effects from light, sound and temperature; and nursing the infant in a well-supported and flexed position.

This review identified a gap in research related to optimising family-centred palliative care for infants who remain on the ventilator until their death. There is an urgent need to recognise ventilator-dependent infants requiring palliative care may remain mechanically ventilated for an indefinite period. Hence, nurses and other health care professionals need clear, evidence-based guidelines to plan care for these infants. These guidelines must range from stringent assessment of symptoms and their early detection, to the prevention and effective treatment of pain and distress specific to infants who remain on mechanical ventilation. Attention should also focus on the support required by parents as they are encouraged to participate in a range of decisions regarding appropriate palliative ventilator care for these infants.

Further research is required to explore the parental decision-making processes involved in the withdrawal of mechanical ventilatory support from the palliative infant. In addition, education of the general community about the concept and definition of palliative care according to the WHO’s recommendations is warranted. This will assist the public to understand that palliative care does not solely relate to end-of-life care, but rather to the care of a person (infant) with a life-threatening illness that will optimise quality of life from diagnosis and can co-exist with curative care.

Conclusion
This review of the literature identified a gap in evidence related to palliative care of the ventilator-dependent infant and their family. Focused research is required in this under-researched area of nursing practice to clarify the needs of this population. The care outlined in this comprehensive literature review provides a starting point to formulate evidence-based clinical guidelines for palliative infants remaining on a ventilator. The comfort of the dying infant is of prime importance in ensuring the best possible palliative care and a death which is humane and dignified for the infant, providing some degree of solace for parents as they live with the death of their infant.

Implications for clinical practice
Nurses are considered a key health professional advocate for an infant and their family because they are the sole health professional to provide continuous, 24-hour care at the cot side. Nurses require clear and comprehensive guidelines to provide optimal, family-focused palliative care for the ventilated infant. This literature review summarises the concepts of evidence-based clinical practice within the existing body of knowledge. It is hoped this will motivate clinicians and researchers to develop appropriate evidence-based care guidelines for this important neonatal population.

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References


The development of an interdisciplinary research agenda at Ngala: an innovative case study

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What is known about this topic
- Developing a research culture requires commitment and leadership.
- International recognition that inter-professional education and practice for vulnerable families is the way forward rather than mono-disciplinary approaches.

What this paper adds
- The development of an interdisciplinary research framework within a community early parenting context.
- A case study example of a partnership between researchers and practitioners.

Abstract

Background Ngala is an early parenting, not-for-profit organisation in Western Australia (WA). Research academics from three universities in Perth had been involved in separate research activities over recent years at Ngala. During 2007, a strategic decision was made to forge formal links and articulate an interdisciplinary research framework to promote a research culture amongst Ngala practitioners.

Aim To describe an organisational case study of the development of an interdisciplinary research agenda within Ngala.

Methods Collaborative methods were used. An action learning project was undertaken over a two-year period with the involvement of researchers, managers and practitioners across the five disciplines of nursing, midwifery, early childhood, psychology and social work. This project focused on the development of a research framework to guide future planning within the organisation.

Findings The development process enabled practitioners, managers and researchers to have conversations about the nominated theories and approaches that inform their work in early childhood and parenting settings, thereby improving the communications between the various disciplines represented. As part of this process, a small action research project was undertaken with practitioners that focused on understanding the barriers staff experienced to approaching research activities and to arrive at potential solutions for these barriers.

Conclusion It was anticipated that with leadership evolving at all levels of the organisation, the resultant research framework would be sustainable into the future and grow the evidence base necessary for a strong platform for practice and research.
Keywords: interdisciplinary, early parenting, research framework, early childhood, research culture, early years, theoretical perspectives and approaches, child health.

 declarations

 Contributorship EB primary author and YH had a key role in editing the manuscript; SB undertook the action research project. All authors had substantial contribution to the conception, design, data collection and analysis and the revision and final approval of this manuscript.

 Ethical approval Approval for the project was given by Ngala Executive and Professional Advisory Committee.

 Competing Interests Nil.

 Introduction

 Ngala is an early parenting organisation in Western Australia (WA) with 200 employees. For over a century Ngala has advocated for and supported families to create nurturing, safe and caring environments for their children. The name Ngala has two meanings in the Aboriginal Bibbulmun dialect – “mother and child” and “we two”. This name honours the land on which the premises are located and also acknowledges Aboriginal holistic ways of working with children, families and communities. Ngala’s services are available to all parents of children aged up to six years in WA.

 The work of Ngala in WA contributes to the population outcomes of sustaining families in challenging times and enabling parenting with confidence. Parents often contact Ngala because they need assistance in some way to parent with confidence. This will vary from receiving information and education, meeting other parents in a group context, through to more specialised support such as the enhancement of a parent–child relationship with small group work or individual counselling. Many parents contact Ngala for issues to do with their children’s sleep, nutrition, behaviour or parental adjustment and/or distress in the early years of life, particularly the first year.

 Towards the end of 2007, dialogue on developing a research framework for Ngala commenced. It involved senior staff at Ngala as well as researchers from key universities already involved in some way with the work of Ngala. The research group involved practitioners and researchers from five key disciplines: nursing, midwifery, social work, psychology and early childhood education.

 Purpose

 The purpose of the research framework was to develop an interdisciplinary research agenda for the work in early parenting and early childhood, and to build relationships with key universities and agencies interested in research in the early years.

 The building of the collaborative relationships using an action research and action learning framework, within a case study of one organisation, Ngala, is described.

 Background

 To develop a research agenda dialogue was necessary to articulate the research framework and to have a common understanding of how interdisciplinary members of the research group were going to work together. This would enable the development of priorities and a future plan for identifying funding opportunities and undertaking activities.

 Interdisciplinary team practice is described as a partnership between a team of professionals and a client in a participatory, collaborative and coordinated approach to shared decision making around health and wellbeing issues. There is international recognition of the benefits of collaborative practice to address the complex interplay between the many factors that affect health and wellbeing. The intent of developing an interdisciplinary research agenda was to guide how research, education and practice is undertaken at Ngala and will be conducted into the future. Collaboration around research activities enables a common understanding of what each discipline brings to the table as well as:

• consideration of power and organisational culture
• shared knowledge of theories and concepts across disciplines
• linkages between different forms of knowledge
• understanding of ethical issues and processes
• provision of a setting whereby there is collaboration between researchers and practitioners.

 In the broadest sense of the word, the definition of research includes “… any gathering of data, information and facts for the advancement of knowledge”. VanDeusen Lukas et al. suggest that strengthening organisations to implement research and evidence-based practice (EBP) can be enhanced through the presence of three interacting components which are: active leadership and commitment to quality; robust clinical process redesign incorporating EBPs into routine operations; and the use of management structures and processes to support and align redesign. Developing a research framework was one strategy that would enable Ngala to advance the knowledge base, underpinning its early childhood and parenting work.

 Study design

 A case study design was used, with the organisation, Ngala, developing the research framework as the unit of analysis (that is, the case). Yin gives different types of scenarios whereby case studies are used for various situations particularly as a research method in social science disciplines. Yin states that the case study method allows researchers to retain the holistic and meaningful characteristics of real-life events such as organisational and management processes, small group behaviour and community change. Yin explains that when using a case study strategy an essential approach is to use multiple sources of evidence, with data needing to converge in a triangulating fashion.
Within the case study design two research methods were used – action learning and action research. Firstly, action learning is used to enhance both individual and organisational performance via structured workplace learning based on real projects that people regard as important in the work environment. Initially “action learning” was developed to encourage “cross-pollination” of managers (external) in similar businesses or organisations through a collaborative and reflective peer network. It has evolved somewhat in recent years and is now used as an effective internal learning model when work teams are effectively engaged to collaborate and work towards a change. Put simply it could be seen as a “share and compare” approach to learning. A cyclical process follows with phases of planning, implementing, observing, reflecting and this cycle repeats many times.

Secondly, action research was used for the practitioner project and is best described as a methodology which supports the implementation of a “change”, whilst also providing an understanding of learning through enquiry. It is often described as an emergent process which takes shape as understanding increases – it is considered to be a repetitious process that takes us forward in our understanding. Because of its participative or collaborative nature, “change” is usually easier to achieve when those most affected by the change are involved in the process.

Methods
As described above, the data strategies informing the research agenda were systematically employed by collaborative methods over a two-year period and included:

• Action learning through inter-professional meetings of the research group to develop the framework, priorities for research and a plan for implementation.
• An action research project with practitioners using focus groups and interviews to inform the above framework and plan.

Leadership from the top and secretariat support are crucial, as is a systematic approach to providing staff with information on the progress of activities. Regular meetings of the research group and the commitment of members enabled progress of the research framework through collaborative discussion and planning sessions. The intent was to develop the objectives, principles, theoretical perspectives and approaches, research themes, priorities and a plan. This occurred alongside a continuation of research activities to assist the group to grow and develop. The benefit of regular membership was a bonus for effective implementation.

In addition, the development of the action research project with practitioners was a necessary component for a holistic organisational approach. This was undertaken over nine months by a practitioner involved in the research group and consisted of two phases with the resultant strategies to guide further direction for the research agenda. Both the action learning with the research group activities and the action research project with practitioners were instrumental in developing the framework of the theoretical underpinnings, research themes, priorities and plan for the research agenda.

Results
The research framework
The framework is presented pictorially in Figure 1. The diagram considers the purpose, principles, theories and approaches and the research themes and activities which contribute to a three- to five-year research plan.

Key principles
The principles for the research framework were to connect and collaborate, develop and change, provide a context and integrate rather than work in isolation. These were consistent with the philosophy of how Ngala works within the organisation using ‘C-Frame’ (Connect, Collaborate and Change), which is a strengths-based, solution-focused approach to working with clients, staff and stakeholders.

‘C-Frame’ is underpinned by strength-based assumptions, specifically that most parents, given the opportunity, support, tools and knowledge:

• want to protect, nurture and socialise their children
• have the ability to care for their children
• can make positive changes
• are capable of learning more about their child’s needs.

The principles for the research framework also informed the way researchers, managers and practitioners worked together and enabled the development of theories and approaches across the disciplines.

Collaborative leadership strategies, energy and commitment were needed by the research group (which represented all levels of the organisation as well as academic researchers) to engage with staff at a number of levels. The ‘bottom up’ approach with focus groups and practitioner champions also assisted engagement over time.

Theories and approaches
The process of development of the research framework involved discussion and teasing out of the theoretical frameworks that all five disciplines used in early childhood and parenting practice.

The theories and approaches that inform the work of early childhood and parenting practitioners at Ngala include:

• Attachment theory and infant mental health, which describe the importance of early relationship forming between infant and care givers and how it affects the emotional development of the child and their future mental health.
• Brain development of the child, which investigates the experiences of nature and nurture and how positive experiences are crucial to healthy brain development.
• Child development theory, which is a description of children in terms of their patterns and stages of development as well as how children respond to the context and culture in which they function.
• Family systems theory, which explains how the family system is made up of interconnected and interdependent individuals each affecting each other.
• The ecological model, which views a child as developing within a complex system of relationships, affected by multiple nested layers of the surrounding environment.

• Social learning theory, which focuses on the learning that occurs with one another in social contexts, primarily gained through observation, imitation and modelling.

• Strengths-based practice, which concentrates on the inherent strengths of groups and organisations and seeks to activate the personal strengths of individuals.

• Cognitive behavioural therapy, which is based on the theory that changing unhelpful or unhealthy thoughts, beliefs and behaviours will bring about positive change for individuals.

• Community development approach, which promotes collective ownership and action within communities to achieve change.

The identification of common theories and approaches by the Research Group and the practitioner Action Research project occurred simultaneously over a number of months. These involved planning, acting, observing and reflecting which were cyclical during this period of time. Once documented, the focus then moved on to the key themes for developing research priorities, which would inform the implementation plan.

Key themes for research priorities
A Delphi study in 2005 by Hauck et al. provided feedback from staff on their priorities for research which enabled further research projects to follow. For this specific project the themes for research were identified through a combination of two sources: a process of workshops with the research group and discussions with staff through the action research project. The following were seven key themes identified to guide the implementation plan: perinatal anxiety and depression; early years development; parent-child relationship; parent skill development; families in community context; workforce development; and historical perspectives of Ngala’s work.

Developing a research culture
During the two-year period of development, the Research Group undertook research activities which enabled the dialogue and common understanding of the framework to evolve. The group acted as a monitor to all activities (research, evaluation and practice development) occurring within the organisation.

A grant was obtained from the Western Australian Nurses Memorial Charitable Trust to undertake an action research project with practitioners to inform the research agenda as well as promote a research culture at Ngala. The aims of the study were to:

• Identify the needs and expectations of practitioners around contributing towards and participating in research activity in order to ensure EBP.

• Identify the barriers perceived and experienced by staff that would inhibit the development of a research culture.

• Identify staff perceptions and attitudes towards participation and utilisation.

**Figure 1. Interdisciplinary research framework at Ngala.**
• Develop strategies in collaboration with practitioners to address the identified clinical needs and expectations around EBP.

The method of fostering practitioner input involved focus groups and individual interviews over two phases. During the first phase, 24 staff participated – 17 through focus groups and seven participated in individual interviews. (Due to small numbers of staff, to protect the confidentiality of participants, we cannot give a breakdown of each individual occupational group.) The questions were centred on how staff perceived research and its relevance and use in practice; how they saw a research culture developing at Ngala and the barriers to attaining this. The data were collated through a process of thematic analysis that was then presented back to the next phase of focus groups and interviews to validate and find strategies that would assist in moving the research agenda forward. In the second phase, 21 staff participated – 13 contributed to focus groups and eight participated in individual interviews. A thematic analysis again revealed the major finding that the majority of staff involved in the study perceived ‘research’ as an academic activity which involved a high level of skill and ‘scientific’ approaches. They described research using words such as “onerous” and “arduous”. Practitioners also placed a high value on research and ensuring that practice is evidence-based, with many expressing that research is vital for retaining credibility as professionals and as an organisation.

The barriers identified by staff were consistent with other studies undertaken. The barriers ranged from perceptions of heavy workloads and having little time to invest in research, to a lack of support by the organisation in providing quiet spaces to study or reflect; as well as the need for training and opportunities to undertake activities.

The recommendations put forward by staff were to:

• Provide project management support and guidance within the organisation to provide support, guidance and advice with research ideas and projects.

• Develop opportunities for regular “research/practice evidence sessions” open to all staff to attend if interested, operating like a research club.

• Offer meaningful incentive and reward for participation.

• Provide access to research databases for all staff, including providing support on how to search and navigate.

• Provide research skills training, including literature reviews or critically appraising research literature.

• Develop processes within the organisation to ensure and support new practice knowledge being translated into practice.

• Allocate time for staff to participate in research activities such as time to read, to share practice knowledge or to take part in projects.

Discussion

Gray highlights the importance of enhancing transdisciplinary research through collaborative leadership. This interest is not new, but can present a challenge when several disciplines attempt to transcend well-established and familiar boundaries of disciplinary silos. Gray promotes a model of leadership that has three general categories: cognitive, structural and processional. The development of the research framework included all three elements and has been a very positive experience. The inter-professional research group and the collaborative efforts have meant that a solid platform has evolved in which to launch a plan and work together in a sustainable way into the future. The benefits and opportunities of having cross-discipline dialogue do increase understanding and tolerance of different perspectives and approaches, both in research and practice. The ‘top down’ and ‘bottom up’ approach needs to occur simultaneously to generate momentum at all levels. The document developed has allowed the articulation of a framework to guide discussion and a focus for research as well as a common language for all service levels, practitioners and researchers. Other authors also substantiate the need for leadership and creating a culture for interdisciplinary collaborative professional practice.

In developing a research culture it is necessary to demystify the concept of research. Through the practitioner forums it was clear that many staff felt research was outside their realm of everyday work. It was encouraging that a number of staff were committed to the development of research in practice and were keen to have education and support to develop their skills in this area. The strategies recommended by staff were about obtaining more support and education in research activities relevant to their work.

Leadership is required at all levels of the organisation to drive change in this area. The benefits of investing in champions to work alongside peers cannot be overstated. Partnerships with the universities created the rigour and education of research to service delivery, as well as providing opportunities to access a greater number of postgraduate students and collaborative research grants.

An implementation plan has been developed and the recruitment of a part-time research officer has been organised to focus the organisation with progressing the strategies identified. A further submission is just being finalised to progress increased rigour within practice and incorporate client feedback in the study and further funding is being sought to ensure its long-term sustainability.

The challenges for working within a not-for-profit organisation, such as resource constraints and capacity ability, can be daunting. Nevertheless, this project has demonstrated that these barriers can be overcome if a small inter-professional group is committed to finding creative solutions to engaging staff in a service that continues to strive for excellence, rigour and relevance to practice. In this instance, leadership, provided by the Research Group is required to stimulate and create energy and ensure the team is united and working in the same direction.
Rogers and Stevens discuss the importance of developing an agenda for practice-based evidence in parenting and early childhood. They propose as key elements for the agenda: organisational and practitioner strategies; researcher–practitioner relationships; inter-organisational cooperation; and involvement of parents and carers.

The involvement of consumers in the development of the research framework has been a weakness to date, but it is acknowledged within the new Ngala strategic plan that the voices of families need to be stronger and inform the work we do at a research level. Ngala will be considering how best to incorporate the voices of parents and children through governance arrangements and research activities, including Indigenous and Culturally and Linguistically Diverse (CALD) communities.

Conclusion

Ngala, a not-for-profit parenting organisation in WA, made a strategic decision to forge formal links and articulate an interdisciplinary research framework to promote a research culture amongst Ngala practitioners. This narrative paper has explained the development of an interdisciplinary research agenda using collaborative methods in an action learning project over a two-year period and involving an interdisciplinary team of researchers, managers and practitioners. The project focused on the development of a research framework to guide future planning within the organisation.

In the development process, practitioners and researchers discussed various theories and approaches that inform their work in early childhood and parenting settings, thereby improving the communications between the various disciplines. The project incorporated a small action research project with practitioners which focused on understanding the barriers staff experienced to approaching research activities and suggested solutions to those barriers. Research leadership evolved throughout Ngala, with a resulting research framework which would be sustainable into the future, and which could develop evidence necessary for a strong platform for practice and research.

The implications of the research agenda for practice areas has enabled a process of change and has anecdotally enabled the progression of some strategies in the support of practitioners and the application of theory and knowledge for them in their work with clients. The Research Group continues to meet on a regular basis and the organisation has now employed a research officer on a part-time basis to progress research activities. The development of the research framework has provided a solid foundation for further research activities.

The process of working with researchers, managers and practitioners continues to evolve and strong leadership continues to be paramount in developing a research culture. It is hoped that the research framework will continue to evolve and grow research and practice development activities into the future.

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References

Tips to help you find, apply for and get grants

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Abstract
To do research means to enter the world of grant applications. Finding funds to conduct your important and relevant research can be a huge task. However, it is worth it as it will contribute to better outcomes for neonates, children, youth and their families. Finding funds means searching for grants, preparing applications, submitting grants, hoping for the best ... then turning around and doing it all over again for the next research question! Sources of funding may be personnel awards such as scholarships/ fellowships/career awards, all of which are funds to support the individual researcher’s salary to conduct research, or support conference attendance or travel to centres of research excellence. Or they may be operating grants to support the conduct of the research, which may be used to pay research personnel or students’ salaries, purchase research equipment or supplies, pay for statistician support or host a research meeting or symposium.

Introduction
This article aims to give new researchers some helpful tips to successful grant applications. The following eight tips are based on the assumption that your intended project is one in which you have expertise and passion, that your project contributes to an important knowledge and research gap, and is scientifically sound.

For further in-depth information and guidance, I recommend the book Successful Grant Writing Strategies for Health and Human Service Professionals1.

Search
Finding funding opportunities and sources requires searching. Possible sources of money to support research will be in places where you expect as well as some other less well-known places. Places you expect to access research funds include the National Health and Medical Research Council site (http://www.nhmrc.gov.au/grants), the Australian Research Council National Competitive Grant Program web page (http://www.arc.gov.au/ncgp) as well as your affiliated universities, hospitals and research institutes. (Just look under grants or research in the search terms.) In addition, most universities and research institutes regularly put out a grants bulletin with information about funding opportunities, both within and outside their organisation. It is worth going through these to see if your research question fits into any of the funding opportunities listed. However, there are numerous other places where health research funding opportunities will be posted or found and it is worth your while to search for these opportunities. First of all, your professional groups, associations and colleges have scholarships and grants aimed at supporting their members to further their research capacity. These grants range from a few hundred dollars from local organisations, up to many thousands for large international organisations. Check the web pages of any professional groups you belong to, or are affiliated with, to see what they have to offer. Scrutinise their research priorities and the eligibility criteria for their grants. Other sources may be philanthropic organisations. There are many organisations which have funds for research, focusing on all aspects of care, from preterm infants, children with cancer, renal disease, orthopaedic conditions, cystic fibrosis, Aboriginal health issues, post-natal depression to young adults. This can be significantly narrowed down to your specific area of interest. Lastly, and very importantly, most large hospitals have research foundations. Talk to the foundation staff about your research. Make sure the relevance of your project is highlighted and your aims are clear. You want to ‘sell’ your project in a way that is understandable to people outside of health care professionals.

Start early
High-quality, clearly written and scientifically sound grant applications take time! Planning ahead to make sure the submission deadlines are realistic for you and your co-applicants and supervisors or directors who need to sign off on your applications is imperative. In addition, many institutions require that external grant applications undergo internal peer review; therefore, ensure your deadline is geared around submitting the full application for internal review. Give your co-applicants and supervisors/directors sufficient time to read your draft proposal, your revised draft proposal and the final draft proposal, and time to get all required signatures.
This process can take longer than expected, so starting early, at least four to six months prior to a large grant, and two to four months prior to a small grant, will optimise the likelihood of everything being prepared in time.

Build partnerships
It is difficult to do research in isolation. High-quality research, which has far-reaching implications for clinical practice, requires a team. It is never too early to start building collaborations and partnerships. Ask your supervisors, mentors and friends to introduce you to experts in the field. Talk to people at conferences during the conference sessions as well as the social programmes. Get to know your librarian/s who are invaluable sources of support for your literature reviews. If your studies require systematic reviews and meta-analyses, invite your librarian to join your research team. It will be their input that is most valuable in ensuring a high-quality, well-planned and executed systematic search of the literature is conducted. Invite a statistician on your team who has expertise in the planned design, conduct and analysis of your research and ensure you are working closely with clinicians, managers and leaders in the field you are going to conduct your research in. Engaging with ‘knowledge users’ who are the clinicians, managers, leaders and consumers, including parents and young people representatives, from the inception of the research question is integral to the success of the planned project. Your knowledge users will help frame the research question and advise you along the way about the feasibility of the project, the outcome measures and the suitability of any planned interventions. In addition, consider collaboration with an individual, or a team with research skills and expertise less related to your clinical topic, but an expert in your methods or analysis. For example, if your proposal relates to utilisation of pain management strategies during early childhood immunisation, consider inviting an expert in the field of knowledge translation to join your new team.

Work with a mentor
Your grant applications will benefit from input from an experienced researcher, either as a co-principal investigator, co-investigator or a reviewer. This may be your supervisor, or co-supervisor/committee member; someone conducting research related to your area. Or if you are part of a research institute, there may be a mentorship programme in place, where an experienced researcher volunteers to mentor less experienced researchers. Take advantage of such experience and sources of support. Arrange meetings with potential mentors to talk to them about your proposal and how they can support you throughout the application process and beyond.

Follow the instructions
This may seem obvious, but following instructions is imperative. Using a smaller font than directed may mean your application is returned to you, unread and rejected. Omitting even a small section of the application may mean the same outcome. Stick to the exact page numbers specified; abide by recommended formatting; include all appendices required; provide letters of support and collaboration as requested; include a detailed budget, budget justification and quotes if requested; and follow the submission processes exactly as per instructions.

Make it clear and interesting
Your idea needs to be ‘sold’. Clearly articulate the need for the study and how your study will contribute to your identified knowledge/research gap. Write a clear hypothesis. Make sure the aims and methods are spelt out, the significance of the study and its relevance to care of children as well as the funding source is clear and ensure the story you tell is interesting. Including pilot or preliminary data where possible substantially strengthens your application, especially for large grants. This shows that you are on a research trajectory relating to the specific question and have tested some of your methods. Importantly, it can make the proposal more compelling and interesting to read. Include measurable outcomes and the project will benefit. Remember that grant reviewers read large numbers of grants. Be kind to the reviewers; make your application clear and interesting. The same preparation principles apply to writing a grant as it does to writing a paper; draft, draft and redraft.

Budget appropriately
Whether your planned submission is a major operating grant or a small travelling scholarship, having an accurately calculated, complete and well-justified budget is integral to a strong application. Check in the application guidelines exactly what the allowable expenses are and obtain quotes whenever possible. Seek advice and review of your budget from your organisation’s grants office or your experienced research mentor.

Seek help from your resources
Finally, utilise your available resources. If you have a grants office or a research institute with available support, request assistance in the preparation of your application as early as possible. Ask someone external to your research area to peer review your proposal, to ensure your proposal is understandable to someone unfamiliar with your field. Ask a mentor or colleague if they would be prepared to share a copy of a recent, successful grant application to read. Attending workshops on successful grant writing and reading books on how to maximise your success. Similar to all writing, grant writing is a skill which improves with practice.

Conclusion
I hope these eight tips to research funding are useful to you in your future grant applications. Good luck with your research. Remember that we, as neonatal, paediatric and child health nurses are in a unique position to utilise and conduct research in collaboration with our fellow health care professionals and community partners, which has great potential to improve outcomes for sick and healthy newborn infants, children, young people and their families. I look forward to reading about your research in the years to come!

References
Cochrane Nursing Care Column

Section Editors Carmel Collins RN, RM, NICC, BSoSc, GDipPH, PhD and Trudi Mannix RN, RM, NICC, BN(Ed), MN(Child Health), EdD.

Each issue of the journal features a summary of a Cochrane Review relevant to neonatal, paediatric or child health nursing. This is an initiative of the Cochrane Nursing Care Network (CNCN). If you would like to be involved in writing a summary, please contact the Section Editors, Carmel Collins (carmel.collins@health.sa.gov.au) or Trudi Mannix (trudi.mannix@flinders.edu.au).

What is a Cochrane Review?
Cochrane Reviews help us to ‘make sense’ of often large amounts of evidence for and against health care treatments and practices. They are specifically designed to help clinicians, patients and policy makers make choices regarding health care interventions. Most Cochrane Reviews are based on randomised controlled trials, but other types of study designs may also be taken into account.

Cochrane summaries are based on new and updated systematic reviews published in The Cochrane Library. The summary must be read in conjunction with the full review when making decisions. The authors’ conclusions are summarised but have not been reinterpreted.

How do I access the full review?
Complete reviews are published monthly by the Cochrane Library and are available at http://www.thecochranelibrary.com/

Cochrane Review summary
High-flow nasal cannula for respiratory support in preterm infants.

Clinical context
In the preterm infant requiring respiratory support for apnoea, respiratory distress syndrome (RDS) or chronic lung disease (CLD), a variety of non-invasive ventilation options are available. Nasal continuous positive airway pressure (CPAP) is commonly used as an alternative to endotracheal intubation and, more recently, high-flow nasal cannula (HFNC) is being used to deliver positive end-expiratory pressure (PEEP), oxygen, blended oxygen and air.

Both methods, however, may have adverse effects, despite being moderately easy to apply and manage. The most significant risks related to nasal CPAP are nasal trauma and distortion of the nares, and for HFNC, mucosal irritation, obstruction, nosocomial infection and possible lung injury from PEEP which is not measured and inconsistent.

The aim of this Cochrane Review was to compare the safety and efficacy of HFNC with other forms of non-invasive respiratory support in preterm infants.

Inclusion criteria
Studies
Randomised and quasi-randomised studies (including crossover trials).

Participants
Preterm infants (<37 weeks’ gestational age) receiving respiratory support after birth with or without a prior period of intermittent positive pressure ventilation (IPPV).

Intervention
HFNC oxygen – defined as the delivery of oxygen or blended oxygen and air via a nasal cannula at flow rates of >1 litre per minute (lpm).

Alternative interventions included: head box oxygen, low-flow (≤1 lpm) nasal cannulae, nasal CPAP, non-invasive IPPV, HFNC using an alternative technique (for example, humidified versus non-humidified, or different models of HFNC).

Outcomes
The primary outcomes included death (prior to discharge), CLD and need for reintubation. Secondary outcomes included duration of respiratory support, length of stay, air leak syndromes, nasal trauma, nosocomial sepsis, gastrointestinal complications, growth, days to full feeds, retinopathy of prematurity and neurodevelopmental outcomes.

Results
Four small trials including 177 infants were identified for inclusion in the review. One study is awaiting assessment and there were a further five studies identified that are currently in progress.

Each study differed in the intervention compared, the flow rate and indication for use:

• HFNC compared to nasal CPAP in preterm infants for treatment or prophylaxis of RDS and post-extubation.

• Humidified HFNC to non-humidified HFNC in preterm infants post-extubation.

• Two types of humidified HFNC equipment used in preterm infants post-extubation.

Risk of bias: Risk of selection bias was generally low, performance and detection bias generally high.

One trial found no difference in the rates of failure in infants treated with HFNC (n=4/33) and nasal CPAP (n=4/34) when used as the primary respiratory support after birth (Relative Risk, RR, 1.03; 95% CI 0.28 to 3.78).

One trial found a significantly higher risk of reintubation in those infants treated with HFNC (n=12/20) compared with nasal CPAP (n=3/20) when used following extubation (RR 4.0; 95% CI 1.33 to 12.05).

There was no significant difference in the need for reintubation in the one trial comparing humidified (n=0/15) and non-humidified (n=2/15) HFNC (RR 0.17; 95% CI 0.01 to 3.34) and
no difference found in the one trial comparing two different models of equipment used to deliver humidified HFNC (RR 1.35, 95% CI 0.31 to 5.90).

For all studies where secondary outcomes were measured these did not differ between groups.

Authors’ conclusions

Implications for practice
Currently there is insufficient evidence to determine the safety and efficacy of HFNC for respiratory support in preterm infants. HFNC may be associated with a higher rate of reintubation when used following extubation than nasal CPAP.

Implications for research
Further randomised controlled trials in preterm infants comparing HFNC with nasal CPAP and other means of respiratory support, or of support following extubation are required. Trials need to be sufficiently powered to detect differences in clinically important outcomes including death, CLD, need for mechanical ventilation and duration of respiratory support. If HFNC is shown to be effective, further research should aim to establish in which subgroups of infants and which type of delivery (for example, nasal cannula size, flow rates, temp).


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Special Issue November 2012 - CALL FOR PAPERS

Mental health for children and young people has an increasing profile in policy and practice and this special issue aims to explore this important topic in relation to early identification, management, service delivery and policy within the contexts of infants, children and young people. The special issue will be published in November 2012.

This special issue is being put together at a time of recognition of the needs of this vulnerable group and their families. We welcome a broad spectrum of scholarly papers, based on research, systematic review or service evaluation, that extend the knowledge base and are relevant to nursing practice for this group. Topics may include the following, although this list is not exhaustive:

- Emerging paradigms in identifying mental health issues in the child and young person groups
- Clinical issues associated with acute illness and/or admission eg first episode psychosis
- Perinatal depression
- Infant mental health
- Service and organisational context and development
- Models/frameworks for mental health care for children and young people
- Outcomes of acute, or community care

All papers should be submitted through the Cambridge Manuscript Management System and the standard guidance for authors should be used: http://www.npchn.com/

We ask all authors to identify the paper as being for the mental health special issue by using the initials ‘MH’ in the title of their paper (e.g. "MH: The Role of the School-Based Counsellor in Early Identification of Mental Health Issues ").

The deadline for receipt of papers is 27 April 2012.

All papers will be subjected to the journal’s usual double-blind peer-review process as set out in the guidance for authors. Should there be too many papers accepted following peer-review for the space available in the special issue, then these papers will be published in subsequent issues of Neonatal, Paediatric and Child Health Nursing.

Professor Eimear Muir-Cochrane, Guest Editor
Professor Linda Johnston, Editor

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